



Annual Letter 2009

At the start of a new year, it is time to review the activities of the *Inflammatory Breast Cancer Research Foundation (ibcRF)*. The following paragraphs will highlight the work of the organization as well as provide some thoughts for the future.

As a member of the Board of Directors for the *National Breast Cancer Coalition Fund*, Kathleen Livingston (ibcRF volunteer) and Ginny Mason (Executive Director) attended the orientation and first Board meeting of the year. Kathleen, the official representative, attends each meeting and provides updates in the monthly e-newsletter from the Foundation. The National Breast Cancer Coalition (NBCC) provides a strong voice regarding the interests and needs of the breast cancer community. As a member organization of the Coalition, ibcRF is part of this dynamic and broad reaching group that helps equip and educate advocates. www.stopbreastcancer.org

In February, Ginny Mason represented the ibcRF at the Amelia Project, a unique breast cancer research consortium held at Indiana University. This one-day meeting brings together clinicians, researchers, and advocates with the goal of providing education and networking opportunities.

For the second year ibcRF exhibited at the Young Survivors conference. The 9th Annual conference was held in Houston and ibcRF board member, Becky Rosen, as well as volunteer Harriet Beckham, staffed the exhibit and attended portions of the conference. Literature was distributed, and visitors to the exhibit received information on the BioBank project. www.youngsurvivorsconference.org

A spring snowstorm welcomed participants to the *American Association for Cancer Research (AACR)* meeting in Denver, April 18-22. Ginny Mason served as a mentor in the Scientist <-> Survivor Program sponsored by the Survivor and Patient Advocacy department of AACR. Mentors work with a group of advocate attendees, helping them navigate the huge cancer research meeting and get the most out of the experience. Participation in this meeting provides opportunities for IBC education and networking with both cancer advocates and researchers. www.aacr.org

The *National Breast Cancer Coalition Annual Advocacy Training Conference* was a great conference, filled with interesting presentations and workshops. A special session honored those organizations that have received Best Practices in Breast Cancer Advocacy Awards. ibcRF joined the other organizations in displaying posters and shared about the BioBank and Clinical Data Base as a model program. This is a "must attend" conference for those interested in breast cancer advocacy work and is held each spring in Washington DC. www.stopbreastcancer.org

Severe weather in September 2008 postponed the Sister's Network 10th Annual National African American Breast Cancer Conference. When the conference was rescheduled to April 2009, Becky Rosen and Harriet Beckham again staffed the exhibit as planned. With the high incidence of IBC in the African American population, this conference is a good opportunity to provide IBC education as well as awareness of the services of ibcRF.

The annual meeting of the *American Society of Clinical Oncology (ASCO)* met in Orlando, FL, May 29 through June 2. This was the 5th year ibcRF was invited to participate in the Advocacy Exhibit area. We were fortunate to have a group of knowledgeable and dedicated volunteers (Gayla Little, Becky Rosen, Harriet Beckham, R.K. VanOrsdal, and Ginny Mason) staff the booth. Along with providing IBC materials and information at the booth, advocates had the opportunity to attend daily advocate programs where the highlights of the day were presented by leaders in the oncology community. The ASCO annual meeting brings together more than 25,000 international participants to learn about the latest developments in the understanding and treatment of cancer. www.asco.org

Also in June, Ginny Mason was honored to join a small group of advocates as faculty at the ***Accelerating Anticancer Agents Validation Workshop*** in North Bethesda, MD. Leaders in clinical and translational cancer research from academia, industry, government agencies, and the advocacy community came together to explore how the development and validation of new anticancer agents can be expedited for the benefit of patients. Bringing together a diverse group of stakeholders allowed for spirited discussions and opportunities to present new ideas. www.acceleratingworkshop.org/

The ***Inflammatory Breast Cancer Research Foundation***, in collaboration with the ***Milburn Foundation***, awarded a grant to Diane Palmieri, Ph.D., of the National Cancer Institute, for the development of a mouse model to study brain metastasis in IBC. We are excited about this joint effort to fund quality research and plan to announce a second grant early in 2010.

Closing the year was the ***32nd Annual San Antonio Breast Cancer Symposium***. While no general sessions were devoted to IBC, there were a number of interesting posters on the subject. Advocates were well represented at this meeting and thanks to the Alamo Breast Cancer Foundation, were able to take part in lively panel discussions each evening reviewing the day's presentations. The symposium ended with a review of breast cancer news and highlights from the year. Each speaker covered a different area and brought their unique perspective to the topic. The presentation is available online and well worth watching. www.sabcs.org

Ginny Mason continues her term on the ***Food and Drug Administration (FDA) Oncologic Drugs Advisory Committee***. Serving on this committee has provided the opportunity to better understand the drug development and approval process, and opened the door to work with a wide variety of people in the broader oncology community. While it is time consuming to review the materials, prepare, travel, and attend the meetings; it remains a unique opportunity to raise awareness of inflammatory breast cancer and the organization. www.fda.gov

In keeping with the times, ibcRF has joined the social networking craze and now has a ***Cause Page on Facebook***, Currently there are over 4000 members joining ibcRF in raising awareness and striving for quality research. Join us on [Facebook!](#)

In 2009 the ***Inflammatory Breast Cancer Research Foundation marked 10 years*** as a voice for the inflammatory breast cancer community. Through our efforts countless people are now aware "YOU DON'T HAVE TO HAVE A LUMP TO HAVE BREAST CANCER", have visited our comprehensive website, participated in the two e-mail discussion lists, received the monthly e-newsletter, had questions personally answered by phone or e-mail, or benefitted from research/clinical trials initiated by ibcRF. The ***Inflammatory Breast Cancer Research Foundation BioBank and Clinical Data Base*** continues to grow. Researchers are interested in using the materials in the BioBank, so it is important that those who are enrolled submit their tissue samples and medical records for this to be a high quality resource. For more information or to participate, contact us at: biobank@ibcresearch.org

WHAT'S IN STORE FOR 2010.....

As previously stated, efforts will be focused on helping those currently enrolled in the ***BioBank and Clinical Data Base*** to submit and bank their tissue samples and medical records. In this era of personalized medicine, it is of utmost importance that the ***BioBank*** be a robust resource for the research community to further the understanding of IBC.

Building on the ***National Comprehensive Cancer Network (NCCN)*** development and implementation of an ***IBC treatment guidelines***, ibcRF has been invited to provide input to the ***Breast Cancer Screening and Prevention*** guideline committee as they review and update the current guidelines.

As an organization dedicated to ***facilitating quality research***, ibcRF has been in conversation with a number of research partners in the development of grant proposals, clinical trials, and other research efforts that have the potential to expedite bench-to-bedside translational research. Information will be presented in the e-newsletter as these projects take shape. Be sure to subscribe to the e-newsletter using the subscription link on the homepage: www.ibcresearch.org

Our annual letter would not be complete without a ***sincere thanks*** to all the dedicated volunteers who make up the Inflammatory Breast Cancer Research Foundation community, as well as our loyal donors who have continued their financial support in spite of challenging economic times. Together we celebrate survivors yet mourn the loss of our pathfinders, all the while remaining....."***COMMITTED TO FINDING THE CAUSE***".

In Gratitude,

The Inflammatory Breast Cancer Research Foundation